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RESEARCH

Como cuidadores de paraplégicos lidam com sobrecarga de atividades no dia a dia

How caretakers of paraplegics deal with the overload of activities on a daily basis

Como cuidadores de parapléjicos manejan la sobrecarga de cuidados en sus actividades diárias

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ABSTRACT

Objective: To investigate how domiciliary caregivers of people with spinal cord injuries deal with the overload of caring on a daily basis. **Method:** This was a descriptive study with a qualitative approach with formal and informal caregivers of paraplegics who are users of two rehabilitation institutions located in the city of Rio de Janeiro. The data were collected using a semi-structured interview and analyzed through thematic analysis of content. **Results:**The reports evidenced two categories:*"Understanding to take care better of another"; and "Evaluating the overload of care for others."* **Conclusion:** The understanding of the conflicts in the person with spinal cord injury must be the premise for the home caregiver to exercise their activities without further damage and overload that could render them unable to meet their needs. **Descriptors:** Overload of the caregiver, Person with disabilities, Spinal cord injury, Nursing in rehabilitation.

RESUMO

Objetivo: Investigar como cuidadores domiciliares de pessoas com lesão medular lidam com a sobrecarga do cuidado no dia a dia. **Método**: Estudo descritivo, abordagem qualitativa, com cuidadores principais e informais de paraplégicos, usuários de duas instituições de reabilitação, localizadas na Cidade do Rio de Janeiro. Coleta de dados a partir de entrevista semi-estruturada e análise temática de conteúdo. **Resultados:** Relatos evidenciaram duas categorias, *"Compreendendo para melhor cuidar do outro"; e "Avaliando a sobrecarga do cuidado para com o outro"*. **Conclusão:** A compreensão dos conflitos da pessoa com lesão medular deve ser premissa para que o cuidador domiciliar exerça suas atividades sem maiores desgastes e sobrecarga que o impeça de suprir suas próprias necessidades. **Descritores:** Sobrecarga do cuidador, Pessoa com deficiência, Lesão medular, Enfermagem em reabilitação.

RESUMEN

Objetivo: Investigar cómo cuidadores domiciliarios de personas con lesiones de la médula espinal manejan la sobrecarga de cuidados en la vida cotidiana. **Método:** Enfoque cualitativo descriptivo, con los cuidadores principales e informales de los parapléjicos, usuarios de instituciones de rehabilitación ubicadas en la ciudad de Rio de Janeiro. Recopilación de datos de entrevistas semi-estructuradas y análisis de contenido temático. **Resultados:** Se analizaron dos categorías, "Comprender a una mejor atención a los demás"; y" Evaluación dela sobrecarga de cuidar a los demás." **Conclusión:** La comprensión de los conflictos de las personas con lesión de la médula espinal debe ser la premisa para el cuidador de casa que realiza sus actividades sin mayores daños y la sobrecarga que le impide satisfacer sus propias necesidades. **Descriptores:** Sobrecarga de cuidadores, Personas discapacitadas, Lesión de la médula espinal, Enfermería en rehabilitación.

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INTRODUCTION

This study was extracted from the master degree dissertation entitled "Knowledge and practices from paraplegic clients and their caregivers on pressure ulcer: Implications for the nursing educational care," authored by Adriana Bishop Alvarez from the Graduate Program in Nursing, Master's degree Course in Nursing, from the Federal University of Rio de Janeiro – UFRJ as a way of broadening the disclosure of the details of her findings. Therefore, this study represents another contribution from academic research to broaden the perspective of students, teachers, and researchers interested in the theme in addition to offering more subsidies to nursing professionals for improved interactions with patients with spinal cord injuries and their caregivers.

It is known that the task of taking care of a dependent family member invariably exposes the individual to a series of adverse situations and entails changes in the lifestyle of the caregiver.[1-3]In the case of this study, the formal and informal home caregivers of paraplegics face a variety of unfavorable factors for the proper performance of their activities whether in the context of specific knowledge that guides this practice, whether by the inadequacy of the environment, which is often incompatible with the proposed needs in terms of personal care and mobility for the paraplegic.

One of the most difficult situations faced by the primary caregiver is the perception of isolation. [4] This results from spending most of his time meeting the needs of the dependent individual and being susceptible to social stress that includes being removed, often from their family and friends, and a sharp limitation on their social conviviality as a consequence.[5.6]

It is imperative to clarify that the term caregiver applies to the reality of persons who work in the prevention, protection, and recovery of health of others, formally or informally, such as care to be provided to persons who are permanently or temporarily unable to perform self-care. The formal caregiver is one who has acquired knowledge in especial trainings concerning the profession, and in general is paid for his services. [1]

With the recent advances in the field of fundamental rights and citizenship of persons with disabilities, which reflect the propositions by the UN Convention on Rights of the Disabled Person, [7] institutional efforts arise in attendance to the clamor of this social segment organized with views on the regular offer of professional training courses for caregivers for people with disabilities considering the growing incidence of functional dependency cases and needs of specific care for these people in the contemporary society.

The function of these caregivers is even more complex because they represent the activity of caring for people with spinal cord injury in the home environment, which require the family member, responsible for the task, inevitable offer of a great part of themselves and their useful time in terms of dedication to that family member who, alone and due to

functional limitations, is in need of assistance for his most diverse essential needs to survive with human dignity.

In this regard, we highlight that medullary lesions are increasingly frequent mainly due to increased urban violence.[8,9] Traffic accidents and injuries by firearms are their most common causes. Spinal cord trauma may result in changes to the motor, sensory, and autonomous functions resulting in partial or total loss of voluntary movements or sensitivity (tactile, painful, and deep) in the upper and/or lower limbs and changes in the functioning of the urinary, intestinal, respiratory, circulatory, reproductive, and sexual systems.[10-1]

In other words, the traumatic aggression results in sectioning or partial or complete disruption of nerve bundles in the spinal cord resulting in sensory, motor, and sexual losses, loss of bladder and bowel sphincters control, and potential complications in the respiratory, circulatory, and thermal functions, spasticity, and pain. [12]These consequences require the person with spinal cord injury to face a new condition of life; the caregiver's presence guarantees that their needs will be met to the extent that they establish a harmonious interaction as social actors in this routine on a daily basis.

It is imperative to draw attention to a wide variety of responses to changes in the lifestyle of caregivers, effects that may differ from individual to individual and in the same individual over time. [13-5] Some caregivers can deal more adequately with the adversities of caring for a dependent family member where as others react in an inappropriate way, often when stress overlaps causing overload. [2]

In fact, the closeness and the kind of bond that exists between the caregiver and the patient before the condition of the person in long-term rehabilitation are also determining factors in the process of adaptation to the new role as caregiver taken on. If a good relationship between them already existed, the trend is that this activity will be well administered and less stressful. When their relationship was marked by conflicts, the care might be provided without proper attention or even trigger feelings of anger from the charges associated with the situation of dependency for daily care. [2]

Faced with the evidences that indicate various effects of overload from activities experienced by caregivers of paraplegics in their households, the present study aims to investigate how domiciliary caregivers of people with spinal cord injuries deal with the overload of care on a daily basis.

METHOD

This was a descriptive, qualitative study conducted with caregivers of paraplegics in the city of Rio de Janeiro. The study subjects were three informal and formal caregivers of people with spinal cord injury, two men and one woman.

The study scenario was composed of two institutions that tend to paraplegics with spinal cord injury namely: a) Rehabilitation Unit from the São Francisco de Assis School Hospital (HESFA) which is part of the Hospital Complex from UFRJ (CHUFRJ); b) the Support Center for Physically Incapacitated Persons (CAIF) from the Paraplegic Club of Rio de Janeiro.

The inclusion criteria were: to be exercising the primary and informal caregiver role for spinal cord injury paraplegic persons, and be over 18 years old. The paraplegic with spinal cord injury should be registered in the rehabilitation service at HESFA or being resident at the Paraplegic Club, and sign an informed consent (TCLE).

The data collection took place in the second semester of 2011 through semi-structured interviews, recorded, transcribed verbatim, and analyzed in accordance with the thematic analysis of content. [16]

The analysis procedure and interpretation of findings included the transcription of the data, for the process of categorization, based on the thematic analysis of content, which unfolded in three phases: pre-analysis, exploration of material, and treatment of results and interpretation.

For the purpose of preservation of the subjects' identity in this study, their identification was coded as mother (CAREG 1-MOM), brother (CAREG-2-BROTHER), and son (CAREG-3-SON).

The study follows the provisions of resolution No. 466/2012 from the National Health Council/MS, which regulates the standards of research involving humans. Thus, the project was submitted to the Research Ethics Committee from the Anna Nery School of Nursing – UFRJ and approved under Protocol No 047/2011.

RESULTS E DISCUSSION

The data revealed that two caregivers (66.7%) are males, and one(33.3%) is female. The age of caregivers was between 20 and 30 years old for two of the caregivers (66.7%),and between 60 to 70 years old for one of the caregivers (33.3%).

One caregiver is literate(33.3%),one had full secondary education(33.3%), and one had incomplete higher education(33.3%). Their professions include one as a homemaker (33.3%), one as a shop operator (33.3%), and one as a construction worker(33.3%).

Two caregivers are not the only caregivers for their clients(66.7 percent); they share some duties with other family members. However, the interviewed caregivers were those who performed most of the care, accompanying well more closely the whole process of care, and were responsible for the care of their clients at home. Only one caregiver (33.3%) was exclusive to one individual. Two caregivers were first timers and one already had some experience and was also the closest family member.

All caregivers participating in this study were related to the paraplegic by blood, which corroborates findings reported in several studies in the literature identifying family members acting as caretakers of family members in rehabilitation.

The analysis of the data, based on the respondents' reports, showed two categories that revealed how caregivers of paraplegics with spinal cord injury deal with the overload of care on a daily basis, namely: *"Understanding to take care better of another"; and "Evaluating the overload of care for the other."*Such categories and its subcategories are listed and described below.

Understanding to better take care of another

- **Learning to care**

The respondents highlight in their speeches that they have accompanied their family member with spinal cord injury from the first moment's post-injury, reporting to the institutions' health teams as the main caregivers for those people, seeking to learn how to take care of them and understand their reactions to the new condition of dependent on their care.

Relevant aspects of learning about how to take care of a paraplegic in their households, frequently assigned to the nurse as the featured professional in this process are highlighted.

> *When he suffered the accident taking two shots, he was admitted to the Clinical Hospital. I had to learn a lot of things there, to bathe him in bed, put on an apron and gloves, and water business there, and the two nurses on one and the other side, and I had to do everything myself. (...) I also learned a lot of things, and I'm always learning understood? (...) We're learning. If we are forced to do, we have to do it. [CAREG-1-MOM]*

> *He remained for along time in the same position in the ER, we couldn't get in to see him, we didn't have access. Then when we had access, he went to the hospital bed then and already came with the bed sores. The doctor took care of him; I had to take his side, and was learning (...) [CAREG-2-BROTHER]*

> *I've learned a few things such as the change of position. Help her taking a bath, when she needs to relief herself, in the hygiene. (...) I feed her and leave her snacks to feed until my dad gets home at night from work. [CAREG-3-SON]*

Besides being anxious to learn how to handle specific situations presented by their family member at home, the respondents also showed advances to understand better how bodies and bodily functions of people with spinal cord injury are organized in the new condition, to help them in their physiological needs.

> *His body was all out of control. It was there in the hospital that it became controlled. He didn't know when to pee or when not to. It was there that they controlled everything. (...)The wound was terrible, but thank God it was never a problem, I always washed, I always cared a lot. (...) And I don't like to wear gloves. So I wash my hands well washed. Then I just do it. Because I don't know how to do things with gloves. It is slippery. [CAREG-1-MOM]*

> *To apply oil at the place where he stays more in contact with in the bed, with the chair, don't stay too long in that position, always keep changing position at certain intervals of time, to avoid the problem, you have to pay close attention at any sign of an outbreak of canker that they sign before showing up, it starts to get dark, red, you have to take care before they arise on site. We also apply ointment and use gauze, two just to protect, because the skin is fragile there, is so fragile... We attempt to protect as much as possible. [CAREG-2-BROTHER]*

> *She can't drink much water because of the hemodialysis. She is careful. And here they do not use too much salt, too much fat. We follow up. (...) For the dialysis we easily take her if she is fed and is cared for. The problem is the spinal cord that gave this problem there. Let's see now with this physical therapy, if it and God help. [CAREG-3-SON]*

- **Evaluating functional gains and limitations**

The study also contributes to the understanding that caregivers value progressive functional gains in their dependent family members; however, they are fearful and insecure about possible complicating factors in the situation of dependency. Some highlighted aspects in cutouts lines from the caregivers follows.

> *He already used the walker did you see? It has two splints there, one is long and big and the other is only from here down, which is the better leg that he has. He was able to walk. But after the CVA. .. [CAREG-1-MOM]*

> *It is really difficult, because she can't stay in one position forever. Sometimes, when she wants to sit, she asks to put her in the little chair and I put. (...) In the morning, there are people at home. I'm going out to work now. Shortly he leaves at one and she stays until 6pmalone. This girl just comes here two days a week. [CAREG-3-SON]*

In the same line of thought, respondents indicated that it is important that their family member engage in the conquest of functional gains, becoming more independent for the full exercise of self-care. Conversely, there was testimony showing the clients' difficulties in actively participating in the process of care and rehabilitation, either because they do not want to face their injuries or make an effort to understand the importance of changing position on the chair as a preventive measure for cutaneous lesions that arise in their bodies.

> *But I tell him to do it, because he stays in bed all day, lazy as hell, he can do a lot, right? Moving the arm. Already has a problem in the spinal cord, will worsen even more. (...) When I say that the wound is bad, he asks to see it. There had been times when he looked and was very nervous. One time he was so nervous ... the wound was deep, I didn't know if it was on the bone, but it was very deep. [CAREG-1-MOM]*

> *He has to help himself even when he sits around for a long time. To avoid other ulcers and worsening of those already in place huh? [CAREG-2-BROTHER]*

> *I can't tell you, because it's just really putting in the chair a few times. Nothing worse happened yet. Then you have to change. When we're at home, we tell her to sit, but she resists a bit, not wanting to sit. [CAREG-3-SON]*

Evaluating the overload of care for the other

- **Body and operational limitations of the caretaker**

The caregivers in this study manifested the following when talking about the special care they need to have with their bodies and bodily functions as well as other commitments outside the home and health provision that guarantees continuing to care for their dependent family members.

> *Previously I did more, today I'm getting weaker understood? I always say that to him. I'm getting older right? I can't take it anymore. I've got tendinitis. There had been days when I caught him on the floor and put him on the bed alone because he fell out of bed and had no one to help him. Today I can't catch him anymore because I have a serious back problem. But I can still take him to the bathroom, and bring him back, it is still possible. [CAREG-1-MOM]*

> *Well. So, the part of caring, making bandages, bathing, taking back and forth, it's cool for me okay? The other part of sometimes seeing blood in the wounds (refers to when blood comes out of injuries) is complicated. Now, to make the dressings and other things to take and bring him are pretty easy. [CAREG-2-BROTHER]*

> *For every person who has some difficulty, it is the duty of the closest person to take care of her. It's not really a very easy task. Especially now that I'm working, I have to have time for her and for my work. Currently, her condition is already well. Now she needs to be cared by someone. [CAREG-3-SON]*

- **Care that curtails self-care**

The commitment of family caregivers can be confused with feelings of pity and overprotection among other exacerbated ways in the functional dependent relationship with the paraplegic causing losses towards rehabilitation. These are some cutouts from the speech of the MOM caregiver.

> *He has many perks. Has a good situation. Food in time understand? Breakfast always on time. He is well taken care of. (...) When he is lying on his belly, while I look for serum or something, I grab something like gauze and place on top of the wound, afraid of something falling on it, a bug. I've always been careful. Even between his toes, I have to dry well-dried. [CAREG-1-MOM]*

- **Influences from the inaccessible environment**

Difficulties to develop activities caring for their loved family members emerged in the home environment when we addressed mobility/accessibility. Caregivers reported inadequate structural problems because most of them are renters.

> *That's because this house is rented. Is not adapted to it. If it were ours, we would adapt it. Open it. This bathroom here has already been ripped off of the shower box. We took the box out to free space for him. If we leave here to rent another house, we have to*

> *look at everything because of him. For us, it could be two floors, a cramped bathroom, but then we need to see a house that serves him. A bathroom that he could enter (...). [CAREG-1-MOM]*
>
> *My last residence before this one was really hard because there were stairs and we had to carry her, sometimes early in the morning when she went to dialysis. In the current house we're able to get around better with the wheelchair, with aramp and everything else, it eased a bit. [CAREG-3-SON]*

Similarly, reports emerged about many difficulties encountered in external environments where the autonomy of access for their relatives with spinal cord injury is hindered.

> *Everything is difficult. It should be better for the paraplegic because buses are not all like this, occasionally one or two pass, the sidewalks, some places they do not have the right entry, people have to help lifting them. There are places that require others to help. Ladders, climbing on the bus. He needs help in many places he goes. Yes, but now he's not going out much. [CAREG-1-MOM]*
>
> *It is difficult because the neighborhood has no asphalt, so in his house (...). So locomotion is hard on the street back and forth, so he almost never goes out, and even indoors, to adapt to the new conditions, it is actually a little hard understand? [CAREG-2-BROTHER]*
>
> *She only goes out to dialysis. (...) Very difficult, the sidewalks...(...) Bus, no way. [CAREG-3-SON]*

The respondents' speeches show that the need to understand what's going on with their family members with spinal cord injury constitutes the first step towards their learning about how to take care of them. Subsequently, and not necessarily in the same order, the assessment of their functional gains and their limitations is believed to be decisive as elements of utmost relevance to planning daily activities to be implemented in their households for their dependent family members.

It is worth mentioning that the socio-demographic profile of caregivers in this study is unusual because most of them are males, adverse to what is suggested in the majority of studies available in the literature reporting that caregivers are generally represented by a female figure, i.e. the mother, wife, or daughter. [5,17- 8,20]

The analysis of the data reveals that the primary caregiver is one who has total or the great responsibility to care for a dependent person at home devoting most of his time, measured in a number of hours a day, in the care of these people, [5]who in the case of this study were paraplegics with spinal cord injury.

Similarly, it was evidenced that the tasks undertaken by the caregiver over time and associated with several factors eventually constitute significant stressors events. Some studies characterize the consequences of these practices and emotional demands of care as such an impact, using the term *burden* with the sense of load, weight, obligation, etc. [20-22]

The way the caregiver takes care of individuals with spinal cord injury, such as the subjects in this study, is linked to the way he understands the act of caring. Therefore, it is important to rethink and assign new meanings to the beliefs and values involved, turning them into benefits to the caregiver himself. The sharing of responsibilities, acceptance of

third-party support, and relay techniques that reduce the caregiver's overload would allow his return to activities and behaviors prior to the illness, such as work, leisure, and self-care. [18]

People with spinal cord injury, such as other people with disabilities or reduced mobility, generally require assistance to carry out everyday activities, and thus, this need of care requires the presence and intercession of their family caregivers whose quality of life may be threatened by the circumstances of frequent care dispensed to those people.[19] Therefore, the specificity of the care being provided by the caregiver is directly related to their preparation for the exercise of the activity of taking care of others influencing the quality of life of both in the context of overall health. [22]Therefore, before situations withrisk of harm to the feeling of well-being, educational approaches must occupy a prominent position in intervention programs. [5]

It is not uncommon to find people who experience major changes in their pattern and life routines, such as some with spinal cord injury; they encounter a lot of difficulties to overcome the post-accident adaptation phases. They are theoretically divided into phase of impact or shock, phase of denial, phase of adjustment or recognition, and reconstruction phase. This latter is the hardest one for people with great attachments to the person they had been or judged they had been to others before the injury, which constitutes an almost insurmountable barrier in the interactional process with their caregivers. [23]

In fact, it is not easy for the caregiver trying to help anyone who has difficulty to renounce the past; they refuse to discover solutions to their new reality, do not look for means to reconstruct the present and organize their future, do not get excited with the results obtained and do not challenge their nature and limits.[23]

The caregivers in this study showed in their testimonies that the tasks of taking care of their loved family members on a daily basis merge with commitments ranging from pleasant to stressful, regardless of the blood relation they have with the paraplegic; however, they are directly related to their responsibilities with work out in the world and their personal aspirations, needs, and demands.

The caregiver should become informed about the network of services available in their area of domicile to meet any need for support in the care for the person under their responsibility. However, the lack of knowledge about the services available, how to access them, and how to deal appropriately with the demand of caring for others is common. The support in these cases should come from the nurses who work in health units in the geographical area, in particular rehabilitating nurses and those working in Family Health Teams (ESF).

In this respect, it is worth mentioning that the caregivers in this study rely on nurses from rehabilitation services network, through which they receive guidance on questions that arise on a daily basis. [9]Nevertheless, they still experience stress resulting from the daily overload of care towards their family members with spinal cord injury.

It is thought that the educational process is substantiated by an educational theory aimed at adults, where nurses must individually evaluate the educational needs of family caregivers and similarly seek balance within the physical and emotional needs of caregivers, always taking into account the patients' disabilities. [20] Understanding that major challenges

are faced by those who need care and help because of functional limitations resulting from relevant neurological lesions.

This study establishes that the decision to assume the care for someone is a conscious one. Although the designation of the caregiver is informal and arises from the dynamics of each family group, the process seems to indicate certain rules and guidelines reflected in four factors: 1) kinship, with greater frequency for spouses, always prefacing the presence of any child; 2) gender shows an atypical character for not having the predominance of women; 3) physical proximity, considering who lives with the person requiring care; 4) and affective closeness, highlighting the marital relationship and the relationship between parents and children.[5]

CONCLUSION

The testimonies of caregivers suggest that they were advised by nurses on aspects particularly circumscribed in the field of knowledge to care for the body and environment, as well as basic knowledge on physiology, anatomy, infection, and bodily functions among others. The speeches also bring other approaches with domains and information that are characteristics of other professionals who work in the area of health.

The caregivers in this study feel unhappy, inefficient, and unsecure most of the times assuming their roles because they do not feel confident on properly serving the basic needs of their family member at home. Thus, considering that they will continue taking care of their dependent family members in their homes, it is essential that nurses from services networks interact and promote family involvement in the preparation of environmental conditions that are favorable to the work of caregivers.

The present study did not intend to deplete such a complex theme, however, contributes to becoming increasingly an object of study in the field of Nursing in Rehabilitation addressing issues that affect the long-term care and domiciliary environments, preferably coordinated, planned, and executed by nurses and having caregivers for family members of people with spinal cord injury as apprentices. Daily and systematic care might generate stress due to the overload of activities when performed without specific guidelines.

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